Title: Family bereavement: A case study of controlled organ donation after circulatory death

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Abstract

Deceased organ donation represents a major source of organs for human transplantation practice. In the United Kingdom as well as other parts of the world, donation after circulatory death accounts for a proportion of all deceased organ donors. Organ and tissue donation emotively takes place in the context of dying, death and bereavement, yet little is known about the family experience of donation after circulatory death. This paper presents a case study of the phenomenon of controlled donation after circulatory death in intensive care. We present a critical analysis of care processes through the lens of a British donor family who participated in a national study of organ and tissue donation. Anonymised family quotes are applied to illustrate specific case issues, and with reference to relevant national guidance and international research. The case portrayed intimate detail of the moment in time when the family experienced the potential for controlled donation after circulatory death, factors that appeared to influence family consent, and the perceived expectations and outcomes arising from the donation decision. Case analysis revealed local compliance with best practice guidance and compassionate end-of-life care whilst supporting organ retrieval. Caring for the grieving family of potential organ donors requires sensitivity and skill. Of importance is a sound professional knowledge and understanding of the clinical care pathway, together with effective teamwork, optimal communication, family and staff support. Further research is required to determine the impact of controlled donation after circulatory death on family grief and bereavement.

Key words: Adult intensive care, bereavement, end-of-life care, families, organ donation

Introduction

The donation of organs from deceased persons has made it possible for organ transplantation to become an established, worldwide life-saving treatment for patients with organ failure (Girlanda, 2016). The potential for organ and tissue donation is observed in patients whose death is diagnosed using neurological or circulatory criteria. A continuing shortfall in the supply of organs for transplantation has led to a growth in the number of countries who now offer a programme of donation after circulatory death (DCD) in addition to the standard model for deceased donation, namely donation after brain death (DBD) (Manara *et al*., 2012). The British Transplantation Society (BTS) view DCD as an additional donation choice and acknowledge the important role it may play in satisfying the patient's wish to be an organ donor or the family's wish to donate at the end of life (BTS, 2013).

The practice of DCD may be controlled or uncontrolled, and there are significant differences between the two forms (Academy of Medical Royal Colleges (AMRC), 2011). According to the modified Maastricht classification of DCD (Thuong *et al*., 2016), uncontrolled DCD (Modified Maastricht Categories I, II) refers to donation from a patient who has suffered a sudden, unexpected circulatory arrest, whereas controlled DCD (cDCD) (Modified Maastricht Category III) refers to the planned withdrawal of life-sustaining therapy, and expected circulatory arrest. Category IV can be controlled or uncontrolled DCD following circulatory arrest in a patient who is brain dead. In the intensive care unit (ICU) cDCD is predominantly Category III patients (Dunne and Doherty, 2011). In the UK, in 2017/18, cDCD contributed 39% of deceased donors overall (National Health Service Blood and Transplant (NHSBT), 2018a). The success of this programme is attributed to the provision of professional (AMRC, 2011; BTS 2013), legal (Department of Health, 2009; The

Scottish Government, 2010) and ethical guidance (AMRC, 2011), and the underpinning principle of routinely viewing cDCD as a legitimate part of end-of-life care (NHSBT, 2018b).

Background

The potential for organ donation frequently takes place in the context of a sudden and untimely critical illness or event, and intense family grief. Consequently, various emotive and unique challenges are faced by bereaved families of potential organ donors (Sque and Long-Sutehall, 2011; Dicks *et al*., 2017). Fulton *et al*. (1977) were the first to explore the impact of organ donation on the grieving process and found that solace and comfort were reported by the majority (Steed and Wager, 1998). However, this seminal research, and subsequent investigations (Cleiren and Van Zoelen, 2002; Bellali and Papadatou, 2006; Merchant *et al*., 2008; Ashkenazi and Guttman, 2016; Kentish-Barnes *et al*., 2018; Kentish-Barnes *et al*., 2019) have largely focused on psychological outcomes in the context of DBD despite implementation of the cDCD pathways of care. Similarly, little is known about the family experiences of cDCD at the time of a sudden bereavement in ICU.

Aim

This case study critically examines the phenomenon of cDCD in intensive care through the lens of a donor family who participated in a UK national study of bereaved families' experiences of organ and tissue donation (DBD and cDCD donors) (Sque *et al*., 2013, 2018). Ethical approval to carry out the study was obtained from the UK Health Department's National Research Ethics Service; Reference 11/WM/0313. The family participants gave informed written consent to participate in a face-to-face, audio-recorded interview, and agreed for their narrative to be used as anonymous quotes in any subsequent verbal or

written presentation of the research. Interview data were subjected to qualitative content analysis (Hsieh and Shannon, 2005). The coding framework was based on established criterion for determining the influences of prior knowledge, experience, attitudes, and beliefs on the donation decision (The Past); the moment in time when the family experienced the potential for organ donation (The Present); and perceived expectations and outcomes arising from the donation decision (The Future) (Walker *et al*., 2013).

In this paper, we present an amalgam of data derived from a research interview comprising two family members who were the next-of-kin, donation decision makers. Throughout, we refer to 'the family' experience of cDCD and integrate relevant UK national guidance and international research to support our analysis and discussion of critical case issues. This approach was deemed conducive to further preserving anonymity and permitted a more in-depth holistic examination of the phenomenon of interest in the context of the family's temporal landscape.

Case description

The patient and family member (R), a 61-year-old man, was admitted to an emergency department following a sudden collapse. Cardiopulmonary resuscitation was commenced at the scene. A diagnosis of brain haemorrhage was confirmed by computerised tomography scan. He was initially cared for in a regional critical care unit, followed by specialist neurological intensive care in a different hospital. R required mechanical ventilation and sedation. He had a further severe brain haemorrhage whilst receiving care in the ICU. The family were aware of their relative's poor prognosis and the intention to withdraw life-sustaining treatments on the grounds of best interests. A formal approach for organ and tissue donation was made in the context of end-of-life care and expected circulatory death.

A decision to consent to organ and tissue donation was reached by consensus within the family.

Case analysis and discussion

The Past

Many public campaigns for organ donation encourage people to make their wishes about donation known to family and friends. Research has shown that this can positively assist grieving families in making a choice about donation (Ralph *et al*., 2014). R had never really discussed donation with his family, but there was a family-held belief that he would have wanted to donate. This viewpoint was supported by recollection that he had a kidney transplant card. In the absence of a discussion, this concrete evidence can assure families in their decision-making (Burroughs *et al*., 1998). A family member was pregnant, and this appeared to conjure feelings of reciprocity in the context of children and babies as potential transplant recipients. Donation-decision making also appeared to be influenced by personal and professional experience of transplantation. An argument of '*we're all going to be cremated anyway*' was also an apparent rational consideration.

The Present

Organ donation was first raised with the family in the context of a medical consultant discussing R's prognosis. Patients suitable for cDCD are commonly those who do not fulfil the neurological criteria for death but nevertheless have brain injuries of such severity as to justify withdrawal of life-sustaining treatments on the grounds of best interests (Manara *et al*., 2012). It was apparent that the family had understood the clinical situation and the possibility of death following treatment withdrawal.

'*They told us that it was only the machines that were keeping him alive. That he was not brain dead, but that if they turned the machines off, his body would not, couldn't sustain life*.'

Professionals in critical care have important roles in helping bereaved families by offering the option of organ and tissue donation and can contribute important sources of comfort and support (Corr and Coolican, 2010). Jawoniyi and Gormley (2015) discuss the value of mandatory education about organ donation and transplantation activity to enable critical care nurses to fulfil their roles in the organ donation process. Knowledge and understanding is essential to recognising potential donors, ensuring timely referral to a Specialist Nurse for Organ Donation (SN-OD), and in providing potential donor and family care. Best practice guidance for approaching the families of potential organ donors advocates the involvement of a SN-OD, and the support of a multidisciplinary team (AMRC, 2011; National Institute for Health and Clinical Excellence, 2011; NHSBT, 2013). In this case, the presence of a SN-OD, a medical consultant and a critical care nurse suggested a collaborative approach to request for organ donation in which the family were presented with donation options by a trained designated requestor (the SN-OD). International evidence suggests that co-ordinator-led approaches achieve higher family consent/authorisation rates (Gortmaker *et al*. 1998; Jansen *et al*., 2011; Hulme *et al*., 2016).

The room where the donation discussion took place was described as '*very basic*', possibly a teaching room. However, the environment was considered '*of secondary importance to the way in which we were spoken to and the caring way in which we were treated.*' Family perceptions of the quality of the approach-request have been attributed to effective communication skills that can be taught and improved (Siminoff *et al*., 2015). The family assumed that someone so catastrophically ill would not be a suitable donor and this,

along with not having thought about organ donation contributed to an initial reaction of shock. At the same time, there was evidence of spontaneity; '*Almost straightaway I knew it was the right thing to do*.' Bellali and Papadatou (2007) suggest decision-making may be instantaneous. However, the process for this family appeared more in keeping with a 'rational stepwise' approach (Bellali and Papadatou, 2007), involving a private discussion and consideration of the facts. The family perceived '*no pressure*' to donate, and ultimately gave consent for donation to proceed; this being the current legal requirement in England in the absence of concrete evidence regarding an intention to donate (AMRC, 2016).

The family described what appeared to be a long wait before treatment withdrawal, without any clear understanding or explanation as to why, although they were given an apology. The long length of time for donation is high among the reasons for families of eligible cDCD patients choosing to decline consent/authorisation (NHSBT, 2018a). Sque *et al*. (2013) identified family distress due to watching and waiting for death to occur. Similarly, discomfort regarding prolonged dying while seeking potential recipients was a source of discomfort for parents who consented to donate their child's organs after circulatory determination of death (Hoover *et al*., 2014). The family in this case explained that '*it didn't alter our feelings about the way things were*' and rationalised the wait; '*it just meant that we were with him longer.*'

A further acknowledged difficult aspect of cDCD is the uncertainty that arises when life-sustaining treatment is withdrawn (AMRC, 2011). The family recalled a conversation about timescales: '*it* [donation] *did depend on how long it took the heart to stop beating*' and understanding of the possibility that this could result in non-donation.

> '*I was thinking … are we putting him through this and they're going to be taking his organs or not taking the organs, and we'd made this go on longer … But presumably it*

would have just been the same whichever way it went wouldn't it really? We would still have withdrawn the treatment.'

A potential donor audit (NHSBT, 2018a) showed that 44% of potential donors did not progress to cDCD due to prolonged time to asystole. Attempted donation can offer families hope amid despair (Walker and Sque, 2016), which in turn draws attention to the possible negative repercussions of non-donation. An American study found that unsuccessful DCD was associated with a broad spectrum of harms as experienced by family members and confirmed by professionals who cared for them. Despite these harms, many families did not regret attempted donation (Taylor *et al*., 2018).

The family accompanied R to theatre and treatment was withdrawn in the anaesthetic room. They emotively described his death as '*Beautiful … very peaceful'* and perceived *'the greatest respect and care*.'

'They silenced [the monitor] *so you didn't actually hear it. And then they took the oxygen of. And then we just saw the monitor getting less. The anaesthetist bagged him for a while, didn't he? … And someone made a noise outside … and they went and told them off. Went and told them to be quiet … And then they said it was time … She just said 'he's gone' didn't she? And then of course they had to move quickly then*.'

Studies involving families of cDCD donors have shown a need for reassurance that their relative will be cared for with respect both during and after the removal of organs and/or tissues for donation (Bastami *et al*., 2016; Sque *et al*., 2018). The family were asked if they w would like to wait at the hospital to see R following organ and tissue donation surgery. They declined but arranged this via the funeral director.

'*I wanted to bathe his eyelids. That's what I wanted to do when I went in because it looked as if they were sticky, but it was the sutures I think that I could see as well, which I didn't like. But I have to put that to the back of my mind because I still know that what we did was right*.'

The Future

In the 12-months following their relative's donation of organ and tissues for transplantation, the family received letters from the organisation responsible for organ donation in the UK (NHSBT). The family knew which organs had been transplanted and understood the outcomes of tissue donation as the use of heart tissue and valves for four babies and one corneal transplant. The letters also kept the family updated about the progress of the transplant recipients. One transplant recipient had died, but it was felt that this person '*had extra time with his family which he wouldn't have had*.' Hearing about the outcomes of donation was described as '*wonderful*' but '*very emotional*.' Knowing recipient outcome and learning that the transplant was successful can help to validate a family's consent to donation decision (Ralph *et al*., 2014).

Donation was conceptualised as a selfless act for which the family did not expect acknowledgment: '*We made that decision for him, but it was an unselfish thing*.' Reflecting on the donation decision, the family said: '*100% the right decision … It was the right decision to make. Definitely, and I would do it again*.' The donation experience also appeared to have positively influenced the donation intentions of the family; '*we've made that decision that our organs will be used.'* The family suggested their act of donation had helped them in their grief and bereavement; it gave meaning to their relative's death in terms of helping others.

> '*Well it makes you think that* [he] *didn't die in vain. He's actually living on … Someone somewhere has benefitted from him*.'

Donation as a meaningful contribution is a commonly observed response among bereaved donor families (Ralph *et al*., 2014; Dicks *et al*., 2017). The meaning-making efforts of families and the value they place on future perspectives are important observations in the context of family-centred care. This is supported by Corr and Coolican (2010) who

suggest professionals involved in organ donation must take care to appreciate how each person's grief is being experienced and expressed.

The family received no further contact from the ICU in terms of bereavement follow-up care. They spoke of support in their grief primarily from family and neighbours, but also in the form of letters and cards of condolence. Evidence suggests that a condolence letter can help some family members of ICU decedents feel supported (Kentish-Barnes *et al*., 2017). The family appeared to appreciate a sympathy card from their General Practitioner practice, and from the SN-OD on the first anniversary of R's death. They were aware of formal counselling services if required and a UK-based charitable organisation offering a wide range of support to donor families. Although this family had not accessed the outreach support available to them, Hoover *et al*. (2014) found that many parents with experience of DCD shared the importance of connecting with others who had experienced death, especially the death of their own child. R's family said that they had chosen to share their experience of cDCD in a research interview to help other bereaved people; particularly those who may also experience the sudden and unexpected death of a relative.

Implications for practice

Caring for the grieving family of potential organ donors requires sensitivity and skill. Of importance is a sound professional knowledge and understanding of the cDCD clinical care pathway, together with effective teamwork, optimal communication, family and staff support. Equally, it is important to supplement procedural competence with a developed understanding of individual and family reactions to loss, grief and bereavement (Corr and Coolican, 2010; Randhawa, 2012). Education and training may be resourcefully challenging to provide, yet consideration must be given to the apparent influence of compassionate

end-of-life care, through which, the desires of the deceased donor, the donor family and the transplant recipients may be positively fulfilled. Critical care nurses are in a privileged position to advocate cDCD in the ICU.

Conclusion

This individual case study provided detailed insights into cDCD in the ICU through the lens of a donor family. The temporal framework of past, present and future dimensions allowed for the identification and consideration of critical case issues. Case analysis revealed local compliance with best practice guidance and compassionate end-of-life care whilst supporting organ retrieval. The bereaved family narrative was a valuable source of experiential evidence for developing knowledge and understanding of potential donor and family care in the ICU. Further, a case study approach provided opportunity to appraise the design and delivery of cDCD programmes at the end of life, and to learn through and from experience-based descriptions. However, we acknowledge limits to the generalisability of our interpretations through the presentation of a single case. Care and support for the bereaved family involved in organ and tissue donation is a relatively under-explored phenomenon. Further research is required to determine the impact of cDCD care processes on family grief and bereavement.

What is already known about this topic

- A shortage of organs for transplantation has led to a growth in the number of countries who offer a programme of controlled donation after circulatory death (cDCD).
- The potential for cDCD frequently takes place in the context of a sudden and untimely critical illness or event, and intense family grief.
- Critical care staff have important roles to play in the organ donation process as providers of potential donor and family care.

What this paper adds

- Contributes to the small body of research about bereaved family experiences of cDCD through case study analysis.
- Provides detailed insight into cDCD care processes whilst supporting organ retrieval at the end of life in the ICU, with reference to UK national guidance and international research.
- Presents the opportunity for ICU staff to learn through and from an experiential case study of cDCD and critical analysis of accompanying case issues.

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Acknowledgement

We sincerely thank this family for their willingness to share their experiences at such a difficult time in their lives. We thank the English Department of Health for funding the research.